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A Phenomenological Study Of The Impact Of Stroke On Marriage: Life Satisfaction And Occupational Performance In Daily Life

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LIVING WITH A CHRONIC CONDITION: PERSPECTIVES OF COLLEGE STUDENTS AT A PUBLIC INSTITUTION OF HIGHER EDUCATION

BY

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in partial fulfillment of the requirements for the degree of

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ABSTRACT

Chronic conditions are ongoing, have a pattern of recurrence or deterioration, and produce consequences impacting an individual's quality of life. An estimated 164 million Americans are expected to be affected by chronic conditions by the year 2025 (Partnership to Fight Chronic Disease, 2016). College students with chronic conditions face unique challenges making it difficult to succeed in traditional degree programs due to unpredictable shifts in wellness. The purpose of this qualitative research was to discover the lived experience of college students with chronic conditions. Eight adult, full-time, traditional university students with chronic conditions were recruited and participated in a one-time, face-to-face interview. Interviews were transcribed verbatim and reviewed for common themes. A line-by-line coding technique for thematic analysis was used in which recurring meaningful similarities were identified. Four overall themes emerged: imposing symptoms, fluctuating routines, balancing identities, and furthering acceptance. This research reveals implications for occupational therapists to promote success within postsecondary educational settings through intervention services such as providing energy and fatigue management education, promoting occupational balance, and skill building interventions to address time management and resilience.

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Introduction

Chronic diseases are ongoing, generally incurable illnesses or conditions, and are typically manageable if detected early and paired with the implementation of healthy lifestyle behaviors (Partnership to Fight Chronic Disease, 2016). The term chronic condition may apply to a wide range of medical conditions, but these conditions require continuous care for an indefinite period of time (Center for Online Education, 2018). Furthermore, O'Halloran, Miller, and Britt (2004) state chronic conditions have a duration which lasts, or is expected to last, at least six months, have a pattern of recurrence or deterioration, have a poor prognosis, and produce consequences impacting the individual's quality of life. While there may not be a widespread accepted definition of chronic conditions, most accept these conditions may be managed, but not cured, and impact quality of life.

While 45% of the United States population has at least one chronic condition, this number is projected to increase to 164 million Americans by 2025 (Partnership to Fight Chronic Disease, 2016). According to the CDC, 6.5% of individuals between the ages of 18 and 44 years in the United States are limited in their usual activities due to one or more chronic conditions (U.S. Department of Health and Human Services, 2018). Additionally, 5.8% of US college students in the Fall 2018 National College Health Assessment reported having a chronic condition such as cancer, diabetes, or an autoimmune disorder (American College Health Association, 2018). This number may underrepresent the number of students with health-related disabilities in the higher education system as many do not identify as having a disability and are, therefore, not counted in disability rolls (Royster & Marshall, 2008).

Literature Review

Chronic conditions are the leading causes of frailty, disability, and death in the United States and hold the potential to worsen the overall health of patients limiting functional status, productivity, and health related quality of life (Megari, 2013). Chronic conditions lead to declines in activities of daily living (ADLs) and instrumental activities of daily living (IADLs), causing individuals to lose independence resulting in the need for assistance from family or paid caregivers, and-or requiring the use of other long-term services and supports (Cameron, 2019). Chronic conditions can cause stress due to disturbing harmony of life, difficulties resulting from symptoms, treatment processes, disruption of family relationships, loss of certain abilities, and change of body image (Mete as cited in Gürhan, Polat, Beşer, & Koç, 2019).

Individuals with chronic conditions also face various psychosocial challenges such as worry, anger, despair, hopelessness, anxiety, self-withdrawal, loss of status in the family and workplace, decrease in self-confidence, fear of death, and fear of being dependent on others (Gürhan et al., 2019; Grandmaison, Watier, Cavard, & Charlier, 2014; Bag, 2014). Furthermore, chronic conditions can affect the ability to participate in work or leisure activities leading to social isolation which is associated with increased rates of anxiety and depression (Gürhan et al., 2019). The loss of certain abilities and feelings of inefficacy may cause hopelessness and despair provoking depression which may induce suicide ideation (Gürhan et al., 2019).

College students' unique challenges with chronic conditions. College students with chronic conditions may find it difficult to succeed in traditional degree programs due to disruptions caused by relapses and unpredictable symptoms (Royster & Marshall, 2008). The invisibility of symptoms adds to student distress as students express concerns of accusations of malingering symptoms and associated fears of not being seen as genuinely ill by university staff (Spencer, Lewis, & Reid, 2018).

The needs of students with chronic conditions are often overlooked by college disability staff who do not understand the unpredictability of symptoms and relapses experienced by the chronically ill. Unpredictable shifts in wellness level lead to loss of spontaneous behaviors, loss of independence and control, and inability to complete college courses. Unlike more traditional and better understood disabilities addressed by specific solutions, such as wheelchair access or hearing aids, chronic illnesses require ongoing flexible accommodations (Royster & Marshall, 2008).

Traditional college programs do not systematically offer students accommodations considering the unpredictable nature of chronic conditions, in part because students do not disclose information about their health conditions and because their needs are not well understood (Royster & Marshall, 2008). Support for the health-related educational needs of students with chronic illness plays a large role in the likelihood of success in college.

Maslow, Haydon, McRee, Ford, and Halpern (2011) found the majority of young adults with childhood-onset chronic conditions are successful in terms of completing high school and having a current job, however, they are at disproportionate risk of poorer educational and vocational outcomes as compared with those without chronic conditions.

When compared to individuals without chronic conditions in their cohort, college students with chronic conditions report greater feelings of isolation and decreased health-related quality of life (Herts, Wallis, & Maslow, 2014). Furthermore, less than one-fifth of young adults with childhood-onset chronic conditions graduate from college and the mean income of these adults is significantly lower than those without chronic conditions (Maslow et al., 2011). Students with chronic conditions are less likely to graduate college and gain employment, and more likely to receive government assistance (Maslow et al., 2011).

Students with chronic conditions are often forced to use their mental energy and time to juggle competing priorities such as balancing academic studies with a social life, alongside the medical requirements of their condition. Attending college with a chronic condition, such as diabetes, involves two types of tasks: the first being developmental in nature (e.g. moving toward autonomy and preparing for adult roles and responsibilities) and the second being health specific (e.g. monitoring blood glucose, managing insulin) (Ravert, Boren, & Wiebke, 2015). Faced with the conflict between the desire to be part of the undergraduate culture and the need to follow a strict medical regimen, students with chronic conditions struggle to negotiate campus climates (Houman & Stapely, 2013). Common stressors associated with the transition to college, such as changes in the environment and increased educational expectations are often exacerbated when combined with the burden of managing a chronic condition (Devins, 2010; Ferro, Gorter, & Boyle, 2015). During a time of desired increased autonomy, limitations on functionality and the requirement of assistance from others often conflicts with student's attempts to be self-sufficient thus increasing levels of illness intrusiveness and distress (Andrews et al., 2009).

The Model of Human Occupation. Kielhofner's Model of Human Occupation (MOHO) (Taylor, 2017) guided the development of this study. MOHO describes a dynamic process in which individuals engage in various occupations providing a framework to understand how people adapt to disability and rediscover satisfying and meaningful ways to live their lives. MOHO explains how people are motivated to perform occupations (volition) and repeat performance over time (habituation). Volition refers to the motivation for occupation and includes an individual's personal causation (one's sense of capacity and effectiveness), values (what one finds important and meaningful), and interests (what one finds enjoyable or satisfying to do). Habituation refers to the process by which occupation is organized into patterns or routines and includes an individual's roles and habits. Individual patterns of action reflect internalized roles in which individuals identify. Performance capacity refers to an individual's physical and mental abilities underlying occupational performance. As occupations are repeated, the individual's subjective perception of his or her own capacity changes (Taylor, 2017).

MOHO encompasses volition, habituation, performance capacity, and the environment to explain how a person engages in occupation as a result of the dynamic and reciprocal interaction between them (Taylor, 2017). The concept of the influential relationships among each of the human components allow individuals to consider the relationship between the human components (volition, habituation, performance capacity, and environment) and how those factors influence the individual's ability to engage in responsibilities as a college student within their chosen college environment. MOHO can be used to explain how students are motivated to pursue higher education, how habits and routines are formed to support or hinder performance within the college setting, and how individual self-perceptions of abilities develop. MOHO: supports occupation focused practice, helps therapists prioritize clients' needs, provides a holistic view of clients, offers a client-centered approach, affords a strong base for generating treatment goals, and supplies a rationale for interventions (Taylor, Lee, Kielhofner, & Ketkar, 2009).

The role of occupational therapy in higher education. Federal laws protect the rights of students with disabilities within postsecondary education. The Individuals with Disabilities Education Act (IDEA) of 2004 enables students with a disability to benefit from an Individualized Education Program (IEP), which specifically states the support services the student will receive (IDEA, 2004). Occupational therapy services are considered a related service if included within a student's IEP plan (Davies, Trunk, & Kramer, 2014). Although this law creates mandatory free educational supports within public school, these supports do not continue beyond high school.

Section 504 of the Rehabilitation Act of 1973 ensures programs receiving federal financial assistance do not discriminate based on disability for otherwise qualified persons and provides "reasonable accommodations" (U.S. Department of Education, Office of Student Rights, 2011). This legislation provides federal funding administered through a public university, ensuring students with disabilities have access to the same accommodations in college they received while in high school.

The Every Student Succeeds Act of 2015 (ESSA) protects disadvantaged students and sets requirements to better equip students for higher education (ESSA, 2015). ESSA “represents the nation’s commitment to equal education opportunity for all students, regardless of race, ethnicity, disability, English proficiency, or income” (Darrow, 2016, pg. 41). These services do not extend past twelfth grade, thus students who require continuing support and resources are at a higher risk for failure within the college setting.

While occupational therapy practitioners support students throughout high school, implementing occupational therapy services in the university setting will not progress without further dissemination of knowledge to the occupational therapy community and academic support services. To reserve a role for occupational therapy in college support services, practitioners will need to illustrate a clear need for additional services on campus and demonstrate direct impacts on factors such as academic performance, health, and graduation rates (Goodman, 2018).

Occupational therapists are most commonly found in K-12 schools (Jackson, 2007) however, occupational therapy practitioners have a unique knowledge base to support individuals within postsecondary education programs. According to the American Occupational Therapy Association (AOTA), occupational therapists, “help people across the lifespan participate in the things they want and need to do through the therapeutic use of everyday activities (occupations)” (AOTA, 2019). Specialized occupational therapy skills include a broad understanding of how disabilities affect participation and ways to address physical, cognitive, sensory, and psychosocial challenges. Expertise in task analysis, task modification, assistive technology, and environmental modification allows occupational therapists to increase occupational participation through providing individualized supports and interventions for students with disabilities to promote access, participation, and success in university settings (American Occupational Therapy Association, 2013).

Occupational therapists provide interventions to adults with chronic conditions utilizing goal setting, problem solving, family or peer-support, modification of tasks, and long-term use of coping strategies (Hand, Law, & McColl, 2011). These interventions are in line with the World Health Organization's (2005) recommendations for health professionals to support self-management of clients with chronic conditions by facilitating coping skills, goal setting, self-monitoring, environmental modifications, self-reward, and social support.

Limitations of current research. Limited evidence exists regarding the provision of occupational therapy services for students with disabilities at the higher education level. Research investigating chronic health conditions in children and young people has often focused on key transition points, such as the move from pediatric to adult healthcare services or developing young people's self-management skills or autonomy in relation to their condition (Cervia, 2013; Heaton, Räisänen, & Salinas, 2016). Other research focuses on specific health care conditions such as inflammatory bowel disease (Tayama et al., 2015), diabetes (Ravert, Boren, & Wiebke, 2015), and asthma (Monaghan & Gabe, 2015) considering the social impact of these conditions on young people's lives. Literature in occupational therapy service delivery with children and young adults has documented a lack of transition services to support students pursuing higher education (Kardos & White, 2005).

Research examining experiences of students with chronic conditions has been conducted to assist academic advisors clarify ways to facilitate personal growth and progress toward a degree of students with unique health issues (Houman & Stapley, 2013) and to examine the impact of a chronic condition support program in the university setting (Royster & Marshall, 2008). Additionally, the impact of chronic disease as predictors of depressive and anxious symptomology in college students with chronic disease has been examined (Mullins et al., 2017). The only known research specifically examining experiences of university students with a chronic health condition was conducted by Spencer, Lewis, and Reid (2018). Semi-structured interviews were conducted at a major university in Australia to advance the understanding of young people's experiences of managing their long-term conditions and to generate new knowledge to reveal implications for supporting the health of university students. While this research provided insight into the perspectives of college students with chronic conditions in Australia, further research is needed to understand college students with chronic conditions unique experiences and to identify ways to sensitively and appropriately respond to their fluctuating health needs within the United States.

Chapter 2

Journal Article Manuscript

Introduction

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Methods

Research design. This study draws on data from a qualitative phenomenological study which sought to generate an understanding of how traditional college students living with chronic conditions experience a public university setting. For the purpose of this study, a chronic health condition was defined as a condition having a duration lasting, or is expected to last at least six months, having a pattern of recurrence or deterioration, and producing consequences or sequalae impacting the individuals quality of life (O'Halloran, Miller, & Britt, 2004). Interpretative phenomenological analysis has emerged from health psychology as a methodological approach for exploring, in depth, how individuals experience and ascribe meaning to a specific phenomenon (Clarke, 2009). Phenomenological analysis offers a useful methodology for therapists to contribute to a deeper understanding of occupation and its relationship to health and well-being (Clarke, 2009). Furthermore, phenomenology differs from other forms of naturalistic inquiry as phenomenologist believe meaning can be explained and interpreted only by those who experience it (Depoy & Gitlin, 2016). According to Creswell (2013), phenomenology describes the common meaning for several individuals of their lived experiences of a concept or phenomenon. Specifically, transcendental phenomenology was utilized for this study in order to provide emphasis on the descriptions of the experiences of participants rather than the interpretations of the researcher. This research design minimizes the interpretations of the researcher and places emphasis on the experiences of study participants. The researcher engages in the process of bracketing to fully examine their own experiences with the phenomenon being studied in order to concentrate on the responses and perspectives provided by study participants. Bracketing is unique to transcendental phenomenology as it allows the researcher to set aside their own experiences and adopt a fresh perspective regarding the phenomenon under examination (Creswell, 2013). Furthermore, in alignment with this research design approach, in order to further increase trustworthiness and decrease bias, the primary researcher maintained a reflexive journal to examine sources of potential biases throughout the research process.

Recruitment. The sample for this study was acquired by utilizing purposive sampling to identify college students with chronic conditions from one public university in Central Kentucky, United States. To maximize participation, paper and electronic flyers about the study were distributed across the campus in which the study took place and posted within relevant social media groups. Potential participants were encouraged to contact the primary researcher to express their interest and obtain further details about the study. To be included in the study, individuals were required to be enrolled as a full-time or part-time, graduate or undergraduate student at the university in which the study was taking place, medically diagnosed with a chronic condition, be of 18 years of age or older, and speak English. Those individuals who were no longer enrolled as a college student, not medically diagnosed with a chronic condition, younger than 18 years old, and/or did not speak English were excluded from the study.

Procedure. Approval to conduct this study was provided by a University Institutional Review Board (IRB) at the study setting through an expedited review process. All participants provided verbal and written informed consent (see Appendix A) prior to participating in the study. Participation was entirely voluntary, and respondents were advised they could withdraw from the study at any time. Participants were provided with the contact details of university-based support services should they wish to follow-up any concerns raised during interviews. Each participant completed a one-to-one semi-structured interview conducted by the primary researcher. A detailed review of the literature on young adults with chronic conditions was utilized to inform the interview discussion guide. Interviews addressed the following broad discussion topic areas: symptoms of diagnosed chronic condition, daily routines, motivation and personal satisfaction, expectations for and planning for college, challenges related to chronic health conditions, the impact on performance as a college student, social relationships, coping skills and resources, resiliency, and future plans (See Appendix B). The discussion guide was initially piloted with one individual not involved in the study in order to confirm clarity of meaning and overall relevance and coherence in relation to the study topic. Interviews were conducted in a quiet meeting room on campus and were between 25-60 minutes long. Interviews were audio-recorded and later transcribed verbatim by the primary researcher. To maintain confidentiality, participants were assigned pseudonyms and all contextual identifiers removed from interview transcripts.

Data analysis. Upon completion of all interviews, the primary researcher transcribed the audio data verbatim by hand using Microsoft Word. Following the transcription process, the primary researcher read each transcription multiple times in order to become immersed in the data and begin the analytical process. While reviewing the transcripts, the primary researcher engaged in memoing in order to record personal notes, comments, and emerging insights to further contribute to the ongoing audit trail. Moustakas' (1994) approach to transcendental phenomenological analysis as described by Creswell (2013) was followed to complete data analysis. Transcripts were reviewed and a non-hierarchical list of significant statements from the data was developed regarding how participants experienced college with a chronic condition. This process of horizontalization treats each statement as having equal worth; and works to develop a list of nonrepetitive, nonoverlapping statements. The significant statements were then grouped into 24 broader "meaning units" describing the content of these statements, before being reduced into 4 final themes and 11 subthemes. The identified themes were the foundation for creating textural descriptions (what occurred using verbatim data) and structural descriptions (how the experience occurred).

Rigor was established using triangulation to ensure credibility and reliability of the data. To establish credibility, member checking with participants and peer review of data analysis with the primary faculty advisor and committee members were conducted. Member checking was conducted with 4 participants from which no new themes emerged. To establish reliability, a full description of the methods utilized throughout the study were provided. To maintain objectivity, the primary researcher kept a reflexive journal and an audit trail throughout the research process to address sources of potential bias, maintain a record of research decisions, and to track progress.

Participants. A total of eight participants took part in the study: five women and three men. In phenomenological research, sample sizes commonly involve no more than 10 participants (Creswell, 2013). The ages of the participants ranged from 19 to 24 years old. The sample comprised full-time undergraduate and graduate students, who self-reported a range of chronic health conditions. Participants ranged from those who were diagnosed with their chronic condition during childhood to those who had been recently diagnosed (approximately 1 year ago from the time of the interview). All participants were interviewed at a time of their choosing, in person, in a quiet and private room located in either the campus library or a university classroom building. Table 1 provides details about the participants' demographic characteristics and health conditions.

Table 1: Participants

Pseudonym	Sex	Age (Years)	Chronic Condition(s)	Age of Diagnosis (year)	Time Since Diagnosis (years)	Mode of Study
Claire	Female	20	Type I Diabetes	3	17	Full-time undergraduate
Aaron	Male	24	Crohn's Disease	15	9	Full-time graduate
Chase	Male	20	Type I Diabetes	10	10	Full-time undergraduate
Anna	Female	19	Non-epileptic pseudo-seizures, anxiety, Obsessive- Compulsive Disorder	18	1	Full-time undergraduate
John	Male	22	Epilepsy	19	3	Full-time undergraduate
Taylor	Female	22	Crohn's Disease	14	8	Full-time undergraduate
Grace	Female	21	Ehlers-Danlos Syndrome	17	4	Full-time undergraduate
Riley	Female	19	Lyme Disease	16	3	Full-time undergraduate

Results

Findings from the data analysis revealed the personal perspectives of college students with chronic conditions including their own self-perception of themselves and their performance, how they acclimate to the ebb and flow of their condition in the higher education setting, and the supports they feel are needed in order to be successful within a traditional college program. From the data analysis, four themes emerged, which are further divided into subthemes (See Table 2). In order to maintain confidentiality, quotations are presented verbatim from participants with their assigned pseudonyms.

Table 2: Qualitative Themes

Themes	Sub-Themes
Imposing Symptoms	• Physical • Emotional
Fluctuating Routines	• Flexibility and adaptability • Remission vs. flare
Balancing Identities	• Downplaying severity • Individual experiences • Strength and resilience • Severity of condition impacts identity
Furthering Acceptance	• Desire for recognition and empathy • Disbelief and misunderstanding of others • Importance of social support

Theme 1: Imposing Symptoms. When discussing individually diagnosed conditions, participants provided a variety of examples in which their condition results in physical and emotional symptoms limiting their desired level of performance. As participants described the symptoms associated with their chronic condition, it became

clear the physical and emotional burden coupled with their diagnosis is not only prevalent but also inconveniencing.

Physical. During the interviews, participants described the detrimental physical consequences they experience and were keenly aware of as they realized their chronic condition was multifaceted and long-term. When discussing her personal diagnosis of Ehlers-Danlos Syndrome, Grace described the physical challenges she faces and how they have impacted her ability to learn by stating:

> I just have the hypermobile part of Ehlers-Danlos syndrome, so it mainly affects just the joints. I have chronic stomach problems. I've had and struggled with stomach ulcers and I have to take medication for it. I have trouble sleeping. I have insomnia and it happens every night. I'll wake up around two or three in the morning and can't go back to sleep so that's kind of hard with school but most everything else is related to the joints so its chronic pain, dislocations, all that kind of stuff.

Like Grace, many participants described their physical symptoms were not isolated to one part of their body but rather produced an overall feeling of ill health. Fatigue, continuous and severe pain, along with weight fluctuation and loss of appetite were reoccurring manifestations of participant's diagnoses providing a constant reminder of the attention required to manage their health in order to decrease the functional restrictions their condition inflicted upon them.

While participants provided examples of symptoms impacting their physical strength and endurance, they also expressed concerns regarding how their condition altered their cognitive processing skills. Riley describes the adverse physical and cognitive impact of her condition saying:

> I had joint pain, and this got progressively worse over time. At first it just felt like the flu. I had my joints hurt just like bone pain almost, muscular pain, I would have headaches, later on I got what they call a brain fog and then I started having memory problems.

For many participants like Riley, their symptoms not only left them in pain but also left them feeling as if their ability to comprehend and process information throughout their daily lives and within the classroom was hindering their performance. Memory challenges and requiring more time to process and react to information left participants feeling as if they were unable to achieve a level of mental alertness and clarity they were once accustomed to. These mental challenges often contributed to the need to adopt new strategies to support learning and daily life such as using a calendar to keep track of appointments and assignments and dedicating extended periods of time to review class materials.

Emotional. When continuing to describe their individual diagnoses, participants expressed the need to manage not only the physical symptoms of their condition but also the mental anguish and emotional burden they endure. Coming to accept their diagnosis while also attending to the medical requirements of their condition left participants feeling confused and defeated. Grace describes the point in which the emotional burden of her condition can sometimes seem too difficult to carry explaining, “I might just break down because I’m so tired and I just want to go to bed. It’s hard. Sometimes you just want to scream “Why me!?” Feelings of stress, anxiety, fear, and depression were frequently noted by participants as they were faced with the task of juggling a wavering health status and the expectations to fulfill personal responsibilities. Furthermore, participants acknowledged although their condition may not require continuous care and attention, the burden of chronic conditions are constant and contribute to a lingering sense of turmoil and apprehension. One participant stated his symptoms were drifting out into the shadows, meaning he was constantly fearing his symptoms would flare, while other participants depicted this emotional state as John stated, “Emotionally it’s kind of like just sitting back there and eating you up.” And Riley stated, “It’s always in the back of my mind. What if I come out of remission and it hits hard? What am I going to do?” The subconscious burden of being diagnosed with a chronic condition clearly impacted participants as they emphasized the physical symptoms can be difficult to cope with, but they were also devoting large amounts of mental energy to anticipating their next encounter with the severe aspects of their condition and questioning how their condition would impact their future.

Theme 2: Fluctuating Routines. When discussing daily routines as a college student, participants expressed they would like to be able to follow a set schedule however, the fluctuations of their health requires the ability to adapt to their current healthcare demands. Claire explains how managing her blood sugar impacts her morning routine stating:

> If I’m low I have to get sugar first and eat as soon as I wake up. If I’m a little higher or in the hundreds I know I can give myself my insulin, wait 10-15 minutes, do my make-up, and then give myself my shot. But it’s all about what’s that first number going to be and then planning the rest of my morning.

While Claire was able to describe checking her blood sugar as soon as she wakes up each morning, the rest of her day was dependent on the first glucose reading. Other participants also expressed not following a set schedule each day, but rather adjusting their schedule in order to accommodate for their health condition and meet their healthcare needs. Some participants described completing assignments ahead of time when they felt well in order to accommodate for days when they felt ill. As Chase expressed, "I plan ahead of when I have to do stuff and I always give myself a little extra time to get it done that way if anything does arise I can roll with it."

Flexibility and Adaptability. Participants stressed the importance of being able to implement coping strategies on most days in which they felt ill, however, they also stressed the importance of taking advantage of the days when their symptoms were not as bothersome.

> On the really bad days I might have to modify my day. The good days are very very rare and when I have them its literally like I'm on speed or something. I feel so amazing and I'm like What is this? and I will literally go to the gym, clean my whole house, run a mile, and I'm like Oh, this is great! and then the next day I'm like Oh, it's gone. –Anna

Anna's description of adapting her day based on how she is feeling demonstrates her excitement to fill her days with productivity when possible. Participants expressed their conditions were unpredictable and required changing their day based on their needs in order to ensure they not only were attending to their health needs but were also meeting coursework requirements. Participants stated each day has its own challenges and they have found the best approach was to listen to what their body needed and address challenges as they arose. Participants were accustomed to a lack of scheduling in anticipation of feeling ill or needing to rest to accommodate for chronic pain and fatigue.

Remission vs. Flare. When discussing routines and their symptoms, many participants expressed extended periods of time of remission or flares of their condition. Participants described changes in routine, increases in health care procedures and appointments, and inability to complete course work to their own satisfaction while experiencing a flare. Additionally, participants expressed periods of remission in which their condition did not have a large impact on their day-to-day lives, symptoms were not as severe, and productivity levels were increased. Aaron describes how flares of his Crohn's Disease requires more time and attention compared to being in a remission stating:

> The Crohn's Disease doesn't really affect me so much on the day-to-day now, but there where times when it was…when I was going through more flare ups that I had to do more as far as meal preparation went because there were a lot of things that didn't agree with me or because I just wouldn't have an appetite for a wide variety of things.

Participants expressed periods of remission allowed them to focus on priorities such as schoolwork, social activities, and exercising, while flare-ups required increased medical care and adaptation of their lifestyle and routines to simply make it through the day.

Theme 3: Balancing Identities. Throughout the interviews, participants expressed managing multiple roles. Participants made the effort to communicate that although they did have a chronic condition, this was not their sole identity. Participants expressed the need to adopt various roles based on their health needs and their responsibilities as a college student. When possible, participants desired to distance themselves from the identity of having a chronic condition but sought to be perceived as "normal." Additionally, participants also expressed the importance of being an advocate for themselves and others facing chronic conditions in order to increase acceptance and raise awareness.

> I was afraid that people would see that and just immediately write me off as one way or view me as a certain way so since it wasn't my sole identity. I wasn't an advocate for it so I was hiding it but now I identify I know it's a huge part of who I am. It doesn't define me, it's just something that is important to me. I'm a person first, but it is important, and people should be more aware of it. –Claire

Participants whose conditions impacted their day-to-day lives frequently viewed their chronic condition as a large part of their identity, while those who were able to distance themselves from their condition preferred to ignore the fact they had a chronic condition until they required medical care. Participants desired for others to look past their diagnosis and appreciate them as a whole person.

Downplaying Severity. Although the participants within the study were all facing chronic conditions, many expressed they felt 'lucky' and were grateful their condition was not more severe. Despite being diagnosed with a chronic condition, participants were grateful for the life they lived and the opportunities afforded to them.

> When I was in the hospital for a couple of days after my first seizure I was just waiting in the bed and I would see kids with cancer and everything like that just constantly walking around the hospital and it kind of made me realize that I can't complain or say woe is me when I have this epilepsy. –John

Many participants expressed their condition ‘could be worse’ and brought attention to individuals who were more limited in their daily activities. In other words, participants had accepted and adopted a familiar sense of volition, habituation, and performance capacity to construct their own desired occupational identity. Distancing themselves from a label of ill health, despite facing their own chronic condition, allowed participants to maintain a preferred identity of well-being in order to portray a sense of normalcy and reduce the sense of limitations felt as a result of their condition.

Individual Experiences. When discussing possible resources to benefit students with chronic conditions, participants communicated unique, individualized experiences despite common diagnoses. Participants were unwilling to speak on behalf of all college students diagnosed with chronic conditions emphasizing each student’s experiences and needs vary. As Aaron stated, “I can’t speak for all chronic conditions. It can manifest so much differently for so many different people” and Grace stated, “Ehlers-Danlos Syndrome…there’s a lot of different types. It’s a group of connective tissue disorders that causes so many different things and it’s different for anyone who has it.” This perspective further emphasizes the participants desire to be viewed as unique individuals rather than being grouped into a diagnosis category.

Strength and Resilience. As a result of their condition and having to adapt to the challenges they have faced, participants discussed the development of strength and resiliency. Participants felt overcoming their own condition gave them the confidence to face challenges in the future. Chase stated, “I can do anything no matter what gets in the way. Diabetes isn’t going to stop me because if you take care of it it’s not really a disability.” While Claire expressed, “I know that I’m a way stronger person than I ever would have been if I hadn't been diagnosed and mentally it's helped me. Definitely physically." Participants felt their conditions resulted in personal growth and development while many expressed their strength and resiliency as a necessity. Participants pointed out the strength and resiliency they demonstrated was not a choice but required in order to succeed in their college programs and to uphold their responsibilities within their personal lives.

Severity of Condition Impacts Identity. Participants responses also reflected their personal identities were dependent upon their health status. While experiencing symptoms, waiting for a diagnosis, or during a flare-up, participants considered themselves to be disabled, however this was not the case during times of remission or times when they felt their condition was well managed. Anna expressed, "I don't really consider myself disabled now but the first six months I did for sure." Some participants felt their condition never resulted in an identity of being disabled or even limited in their daily lives, however all participants did express their chronic condition would always contribute to at least a small part of their identity.

> I don't come out and just tell people right away. It don't really bother me it's just who I am I guess. It's not really a disability. It's a disease. It is part of me. It's always gonna be there but it doesn't hinder me. -Chase

For many participants, telling others about their chronic condition during a time of remission or when their symptoms were well-managed was not a priority or necessity as they felt it would cause others to view them with pity or treat them differently as a result of their diagnosis.

Theme 4: Furthering Acceptance. When discussing supports and resources participants felt would be beneficial to support college students diagnosed with chronic conditions, some mentioned small changes to the institutional setting such as improving food storage and meal plan options and allowing for more flexibility when scheduling classes and within curriculum programs, however participants main desires were psychosocial in nature. Participants expressed their greatest desires were associated with the invisibility of their condition and lack of understanding not only within society but by university staff and medical professionals. Taylor stated, "I'll tell whoever, whenever about it, whoever wants to know. It's getting it out there, people can hear about it and know about it." While Claire described the importance of being an advocate stating, "To me, no question is ever dumb. I'll answer any question. I think it's important for people to know." Many expressed feelings of responsibility to serve as an advocate not only for themselves but for other students who were also diagnosed with chronic conditions. Participants felt increasing awareness would help improve the supports and accommodations provided to individuals with chronic conditions.

Desire for Recognition and Empathy. Participants also expressed feelings of loneliness and invisibility. The desire for emotional support and compassion for the challenges they face was evident. Grace expressed, "You want someone to feel what you're going through for just a minute so they can understand it and sometimes I really do wish that I knew someone who had what I had and could relate." While Anna explained, "I want someone to take an interest in my situation and actually give a shit about it." Some participants explained they felt society and the campus community did not care about their condition and had no desire to provide support services. Participants had accepted their diagnosis and had found ways to cope in order to support their success within their classes, however they still felt the emotional burden they carried hindered their ability to develop meaningful social relationships.

Disbelief and Misunderstanding of Others. When discussing common misconceptions about college students with chronic conditions, participants felt due to the invisibility of their condition they had to prove their ill health to medical professionals, professors, and university staff. Participants told stories of professors accusing them of making excuses after they had missed class or an assignment deadline and medical professionals accusing them of seeking unnecessary medical treatment.

> People in general just don't really understand nor do they see it as something that is as important as something physical. If I was in a wheelchair people would be way more likely to want to help me, to take my problem seriously and to accommodate me and to do everything they could to help me than something that you can't see and I think that's just how it is around every invisible illness whether it be mental illness or something that goes on inside of your body that no one else can see. People just don't understand that they're just as real and just as valid as any other type of illness. –Anna

Participants felt others were less likely to attempt to have empathy for their condition or accommodate their needs due to the unpredictability of their health status. Some expressed they no longer sought to explain their condition to others as individuals who were not diagnosed with a chronic condition simply were not willing to or able to relate to their own experiences.

Importance of Social Support. While participants expressed taking advantage of on campus resources such as the student accessibility office and the recreation center, participants felt their biggest resource was the support they received from family, friends, and professors. This support motivated them to continue to pursue their college education, despite facing additional challenges related to their condition. Riley described the importance of social support stating, “My friends and my parents being like ‘You’ve done this. You can do it again. It’s going to be okay.’ Just kind of backing me is really comforting.” While John expressed, “The group of friends that I have. They’re all willing to watch over me because I have like 40 guys on my back which is probably in my line the biggest resource.” Some participants told stories of roommates driving them to receive medical treatment, professors who took time to reach out and provide extra resources and support, friends who would advocate on their behalf, and family members who helped monitor their condition using technology on their cell phones when hours away from the student’s campus. Two participants expressed they would not have been able to make it through their first semesters of college without the support and assistance provided to them by their sisters who were either attending the same university or living within the same community. These stories emphasize the overall importance of raising awareness, acceptance, and understanding so students with chronic conditions can have access to the social support they feel is such a vital resource.

Discussion

The findings from this research contributes to the lack of current literature revealing the challenges and personal experiences of college students diagnosed with chronic conditions who are pursuing a degree in a public university. The analysis reveals although participants are aware of their condition and healthcare needs, additional efforts are made in order to increase the likelihood of a what students perceive to be a normal college experience. These efforts include implementing independent coping strategies and withholding disability identification status to avoid differential treatment and feelings of pity from others. Although participants preferred to adopt a positive mindset and minimize the impact their condition had on their lives, periods of ill health and flare-ups hindered students' ability to participate fully in university experiences to their desired degree. In this study, participants expressed living with a chronic health condition while attending college required constant management of symptoms and carrying additional mental and emotional burdens.

This study revealed students with chronic conditions in the university setting face both physical and emotional symptoms resulting in limitations upon participation and the need to accommodate fluctuating daily routines consistent with previous literature (Royster & Marshall, 2008). While students would prefer a set routine when attending university and seeking medical care, the unpredictability of their condition required addressing daily challenges as they arose and increasing medical care during flare-ups and increasing symptom severity. The challenges students with chronic conditions face create occupational and performance barriers currently not being addressed by traditional university disability services. This study aligns with previous research findings in which managing the many aspects associated with a chronic condition exacerbates the stress levels already associated with pursuing a college education (Devins, 2010; Ferro, Gorter, & Boyle, 2015).

In alignment with the research by Spencer, Lewis, and Reid (2018), these results reveal students are reluctant to identify as having a disability or requesting additional support services for fear of accusations of faking their illness or malingering symptoms. These students desire to engage in what they view as the typical college experience in the same ways as their peers who do not have chronic conditions in order to portray an occupational identity of health. By not reporting their conditions to accessibility offices or professors, students are able to portray an identity of good health. The participants social contexts impact their occupational performance, health and wellness, and their occupational identity. Participants feel as if they can manage their condition using self-management and coping skills since facing a lack of understanding and awareness from others leads to more questioning contributing to increasing levels of stress and anxiety. While choosing not to disclose their condition may allow students to adopt a self-perception of normality and engage in a more stereotypical college experience, this may lead to a lack of support services from professors and university staff. Feelings of a desire for normalcy while balancing a medical regimen is consistent with previous research demonstrating this is a common experience for college students with chronic conditions (Houman & Stapely, 2013).

Due to the expressed need for increasing awareness and acceptance, greater social support, and the retelling of experiences of disbelief and misunderstandings, it is clear greater understanding and awareness of chronic health conditions is needed. Participants expressed the need for flexible accommodations tailored to their own fluctuating health needs; thus, university staff and support services must be educated on these student's unique experiences and needs. This is consistent with previous literature discussing possible support services for college students with chronic conditions (Royster & Marshall, 2008). By increasing the awareness of these invisible conditions, university staff may be able to provide support services students with chronic conditions would be willing to seek out without feelings of anxiety, fear, and defensiveness to prove their own health needs. Despite the invisibility of their conditions, students identify the need to be considered equally for support services in the same capacity as their peers who are accommodated for visible physical disabilities.

This research provides evidence to identify the need to address personal performance skills possibly hindered by occupational performance barriers such as imposing symptoms, social contexts, and environmental barriers. Furthermore, the participants individual experiences, including their unique aspects of volition and personal causation, calls for client-centered occupational therapy services in order to further enhance the student's performance skills and to help students achieve their desired occupational identity.

Implications for Occupational Therapy Practice

As occupational therapy is a health profession focused on enabling people to participate in meaningful occupations (World Federation of Occupational Therapists, 2019) such as pursuing higher education, it is well positioned to work collaboratively within higher education settings to support successful and inclusive university experiences (Pereira, 2012). Occupational therapists can promote the completion of higher education programs by addressing occupational performance challenges and other barriers. Occupational therapists could deliver this outcome by enhancing student's abilities to participate in various occupations within the university setting, or by modifying the environment to better support their participation. Implementation of occupational performance coaching programs on university campuses would enable occupational therapists to act as coaches, informants, and guides while eliciting or enhancing strategies utilized by the students. Occupational performance coaching adopts a unique focus on changing occupational performance by providing emotional support, information exchange, and a structured process guiding the overall direction of interactions (Alcorn & Broome, 2014). Occupational performance coaching has a strong potential for application in chronic disease self-management as therapy goals frequently include a change in performance of occupations.

Using student-centered goals, evidence-based practices, and implementing occupational therapy models, such as the Model of Human Occupation (Taylor, 2017), occupational therapists can provide interventions aligning with the scope of practice to provide person-, occupation-, and justice- centered intervention approaches. Occupational therapists can also positively, productively, and collaboratively work together with partners such as academics, support workers, and institutional departments to further enhance a student's educational and broader occupational needs. Enablement and intervention strategies from an occupational therapy perspective go beyond traditional disability support service provisions focused on providing reasonable adjustments with class materials, equitable exam provisions, and other access needs but rather use a holistic approach to address higher education settings' goals for social inclusion, filling urgent transition gaps, as well as enabling such settings to become accountable by providing the best opportunities for their students.

Due to the diversity of training and experience occupational therapists acquire, they are well equipped to provide comprehensive support services to college students diagnosed with chronic conditions. In order to be successful within this role, occupational therapists must consider the impact disability and other health or psychosocial issues can have on the occupations in which students engage and the occupational performance barriers they may face such as the environment and social contexts. Using assessments and activity analysis, occupational therapists can tailor interventions to a students' identified strengths and goals throughout the therapeutic process to maximize the potential of educational success, smoother transitions and well-being.

Currently, there is a misconception the enablement and intervention strategies that would be provided by occupational therapists such as chronic illness self-management techniques, energy and fatigue management education, the development of emergency management plans in context with individual health needs, skill building interventions to develop resilience, occupational balance, and time management, and environmental assessments and recommendations are currently provided by student support services through institutional accessibility and disability offices. However, disability support services are general in nature focusing on support services to provide reasonable accommodations with class materials, exams, and other access needs in line with the United States National disability education legislation requirements (Royster & Marshall, 2008). As a result, occupational therapy services within the higher education setting go beyond traditional disability support services.

While working as an occupational therapist within higher education settings beyond generic roles is a relatively new approach towards student support service provision, the potential opportunities are continuously emerging. With the increase of individuals diagnosed with chronic conditions enrolling in college, higher educational settings must move to provide support services reaching beyond reasonable accommodations and provide services to promote supportive learning environments for all students. Due to the holistic nature of occupational therapy and the reputation it has gained in other areas of educational support, it is optimally suited to address secondary education settings' goals for social inclusion, filling urgent student transition gaps, as well as enabling such settings to become accountable by providing the best opportunities for their students.

Limitations

Timing and depth of the interviews was a limitation of this study. Given the primary researcher had a limited window during which to complete the study and meet graduation requirements, saturation of data was not reached. It should also be noted the primary researcher has personal experience with the research topic which may have resulted in researcher bias. In order to counteract this, the primary researcher engaged in reflexive journaling to set aside her own experience of the phenomenon so the focus could be directed toward the participants in the study.

Implications for Further Research

Future research needs to be conducted in order to obtain a greater understanding and awareness of chronic health conditions. Conducting research similar to this study including college students with chronic conditions from multiple universities across various geographical settings will allow for greater generalizability. Research is also needed in order to evaluate the effectiveness of occupational therapy interventions for college students with chronic conditions to demonstrate the potential benefits occupational therapy therapeutic interventions can have on a student's occupational potential and occupational performance. Furthermore, continuing to explore how occupational therapists can utilize their unique skill set to contribute to the higher education setting is needed. Identifying ways in which occupational therapists can collaborate with other professionals in the university setting on a multidisciplinary team may further contribute to successful student outcomes such as identifying an efficient and accurate referral process for occupational therapy services. Research regarding the impact of training and health education for university staff and students may also help foster a greater level of understanding and awareness, thus encouraging young people to seek out needed support without the fear of facing disbelief or lack of understanding.

Conclusion

The intent of this research was to understand the lived experience of college students diagnosed with a chronic condition at a public institution of higher education. Findings suggest more research is needed in order to identify ways to accommodate the fluctuating health needs of college students with chronic conditions and evaluate the effectiveness of occupational therapy intervention services for these students in order to address occupational barriers and increase occupational performance and satisfaction. Greater understanding of chronic conditions is needed, including how these experiences vary based on diagnosis, college setting, timing of the diagnosis, and nature of the health condition. This study identifies the common occupational barriers participants face, how they perceive their own understandings and experiences of disability, and what resources would be beneficial to support success within the higher education setting. As more individuals with chronic conditions enroll in higher education programs, academic support services, university staff, and health care providers should be aware of their experiences related to occupational performance and work toward providing services to promote supportive learning environments for all students to flourish and feel they can contribute to their educational communities. Implementing occupational therapy services within the higher educational setting allowing occupational therapists to serve students holistically, beyond generic roles, can clearly contribute to accomplishing this goal.

References

Alcorn, K. & Broome, K. (2014). Occupational performance coaching for chronic conditions: A review of literature. *New Zealand Journal of Occupational Therapy, 61*(2), 49-56.

American College Health Association. (2018). *American college health association-national college health assessment II: Reference group executive summary fall 2018* [PDF file]. Retrieved from https://www.acha.org/documents/ncha/NCHA-II_Fall_2018_Reference_Group_Executive_Summary.pdf

American Occupational Therapy Association (2019). *About occupational therapy*. Retrieved from https://www.aota.org/About-Occupational-Therapy.aspx

American Occupational Therapy Association. (2013). *Students with Disabilities in Postsecondary Education Settings: How Occupational Therapy Can Help* [Fact sheet]. Retrieved from https://www.aota.org/About-Occupational-Therapy/Professionals/CY/Postsecondary-Education.aspx

Andrews, N. R., Chaney, J. M., Mullins, L. L., Wagner, J. L., Hommel, K. A., & Jarvis, J. N. (2009). The differential effect of child age on the illness intrusiveness–parent distress relationship in juvenile rheumatic disease. *Rehabilitation Psychology*, *54*(1), 45–50.

Bag, B. (2014). Kanser Hastalarında Depresyon. *Current Approaches in Psychiatry / Psikiyatride Guncel Yaklasimlar*, *6*(2), 186–198.

Cameron, K. A. (2019). Chronic Conditions, from A to Z: Life expectancy is lower in America than in other developed nations, mainly due to the toll of chronic conditions, many of which are preventable. *Generations*, 8–12.

Center for Online Education. (2018). *College Students Living with a Chronic Condition.* Retrieved from https://www.onlinecolleges.net/for-students/chronic-health-issues/

Cervia, J. S. (2013). Easing the transition of HIV-Infected adolescents to adult care. *AIDS Patient Care & STDs*, *27*(12), 692–696.

Clarke, C. (2009). An introduction to interpretative phenomenological analysis: A useful approach for occupational therapy research. *British Journal of Occupational Therapy*, *72*(1), 37–39.

Creswell, J.W. (2013). Five qualitative approaches to inquiry. In J.W. Creswell (Ed.), Qualitative inquiry and research design: Choosing among five approaches (3rd ed., pp.69-110). Thousand Oaks, CA: SAGE.

Darrow, A. (2016). The every student succeeds act (ESSA). *General Music Today, 30*(1), 41-44.

Davies, S. S., Trunk, D. J., & Kramer, M. M. (2014). Traumatic brain injury and the transition to postsecondary education: Recommendations for student success. *School Psychology Forum, 8*(3), 168-181.

DePoy, E., & Gitlin, L. N. (2016). *Introduction to research: Understanding and applying multiple strategies* (5th ed.). St. Louis, Mo: Mosby.

Devins, G. M. (2010). Using the Illness Intrusiveness Ratings Scale to understand health-related quality of life in chronic disease. *Journal of Psychosomatic Research*, *68*(6), 591–602.

Every Student Succeeds Act of 2015, Pub.L. 114-95 §114 Stat, 1177 (2015-2016).

Ferro, M. A., Gorter, J. W., & Boyle, M. H. (2015). Trajectories of depressive symptoms during the transition to young adulthood: The role of chronic illness. *Journal of Affective Disorders*, *174*, 594–601.

Goodman, L. (2018). Occupational Therapy in Higher Education. *Communique*, (1), 16–17.

Grandmaison, G. L., Watier, L., Cavard, S., & Charlier, P. (2014). Are suicide rates higher in the cancer population? An investigation using forensic autopsy data. *Medical Hypotheses*, *82*(1), 16–19.

Gürhan, N., Polat, Ü., Beşer, N. G., & Koç, M. (2019). Suicide risk and depression in individuals with chronic illness. *Community Mental Health Journal*, *55*(5), 840–848.

Hand, C., Law, M., & McColl, M. A. (2011). Occupational therapy interventions for chronic diseases: A scoping review. *American Journal of Occupational Therapy*, *65*(4), 428–436.

Heaton, J., Räisänen, U., & Salinas, M. (2016). “Rule your condition, don’t let it rule you”: young adults’ sense of mastery in their accounts of growing up with a chronic illness. *Sociology of Health & Illness*, *38*(1), 3–20.

Herts, K. L., Wallis, E., & Maslow, G. (2014). College freshmen with chronic illness: A comparison with healthy first-year students. *Journal of College Student Development*, *55*(5), 475–480.

Houman, K. M., & Stapley, J. C. (2013). The college experience for students with chronic illness: Implications for academic advising. *NACADA Journal*, *33*(1), 61–70.

Individuals with Disabilities Education Improvement Act of 2004, Pub.L. 108-446, 20

U.S.C. § §1400- 1482. Retrieved from http://idea.ed.gov/part-c/downloads/IDEAStatute.pdf

Jackson, L. L. (2007). *Occupational therapy services for children and youth under IDEA*. American Occupational Therapy Association.

Kardos, M., & White, B. P. (2005). The role of the school-based occupational therapist in secondary education transition planning: A pilot survey study. *American Journal of Occupational Therapy*, *59*(2), 173–180.

Maslow, G. R., Haydon, A., Mcree, A. L., Ford, C. A., & Halpern, C. T. (2011). Growing up with a chronic illness: Social success, educational/vocational Distress. *Journal of Adolescent Health*, *49*(2), 206–212.

Megari, K. (2013). Quality of life in chronic disease patients. *Health Psychology Research, 1*(3)*,* 141-148. doi.org/10.4081/hpr.2013.e27

Monaghan, L. F., & Gabe, J. (2015). Chronic illness as biographical contingency? Young people's experiences of asthma. *Sociology of Health & Illness*, *37*(8), 1236–1253.

Mullins, A. J., Gamwell, K. L., Sharkey, C. M., Bakula, D. M., Tackett, A. P., Suorsa, K. I., … Mullins, L. L. (2017). Illness uncertainty and illness intrusiveness as predictors of depressive and anxious symptomology in college students with chronic illnesses. *Journal of American College Health*, *65*(5), 352–360.

O'Halloran, J., Miller, G. C., & Britt, H. (2004). Defining chronic conditions for primary care with ICPC-2. *Family Practice*, *21*(4), 381–386. https://doi.org/10.1093/fampra/cmh407

Partnership to Fight Chronic Disease. (2016). *The Growing Crisis of Chronic Disease in the United States* [Fact sheet]. Retrieved from http://www.fightchronicdisease.org/sites/default/files/docs/GrowingCrisisofChronicDiseaseintheUSfactsheet_81009.pdf

Pereira, R. B. (2012). The potential of occupational therapy services for students with disabilities within tertiary education settings. *Australian Occupational Therapy Journal*, *59*(5), 393–396.

Ravert, R. D., Boren, S. A., & Wiebke, E. (2015). Transitioning through college with diabetes: Themes found in online forums. *Journal of American College Health*, *63*(4), 258–267.

Royster, L., & Marshall, O. (2008). The Chronic Illness Initiative: Supporting College Students with Chronic Illness Needs at DePaul University. *Journal of Postsecondary Education and Disability*, *20*(2), 120–125.

Spencer, G., Lewis, S., & Reid, M. (2018). Living with a chronic health condition: Students' health narratives and negotiations of (ill) health at university. *Health Education Journal*, *77*(5), 631–643. https://doi.org/10.1177/0017896917738120

Tayama, J., Nakaya, N., Hamaguchi, T., Saigo, T., Takeoka, A., Sone, T., … Shirabe, S. (2015). Maladjustment to Academic Life and Employment Anxiety in University Students with Irritable Bowel Syndrome. *PLoS ONE*, *10*(6), 1–10.

Taylor, R. R. (2017). *Kielhofner's model of human occupation* (5th ed.). Philadelphia, PA: Wolters Kluwer.

Taylor, R. R., Sun Wook Lee, Kielhofner, G., & Ketkar, M. (2009). Therapeutic use of self: A nationwide survey of practitioners' attitudes and experiences. *American Journal of Occupational Therapy*, *63*(2), 198–207.

U.S. Department of Education, Office of Civil Rights. (2011). *Students with disabilities preparing for postsecondary education: Know your rights and responsibilities* (rev. ed.). Retrieved from http://www2.ed.gov/about/offices/list/ocr/transition.html

U.S. Department of Health and Human Services. (2018). *Summary health statistics: National health interview survey* [PDF file]. Retrieved from https://ftp.cdc.gov/pub/Health_Statistics/NCHS/NHIS/SHS/2018_SHS_Table_P-2.pdf

World Federation of Occupational Therapists (2019). About WFOT [Online]. Retrieved from https://www.wfot.org/about

World Health Organization. (2005). *Preventing chronic diseases: A vital investment.* Retrieved from https://www.who.int/chp/chronic_disease_report/contents/e

APPENDICES

Appendix A: Consent Form

Consent to Participate in a Research Study

Living with a Chronic Condition: Perspectives of College Students at a Public Institution of Higher Education

EKU
Institutional Review Board
Protocol Number
2515
Approval Valid
6/12/20-5/10/20

Key Information

You are being invited to participate in a research study. This document includes important information you should know about the study. Before providing your consent to participate, please read this entire document and ask any questions you have.

Do I have to participate?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering. If you decide to participate, you will be one of about 10 people in the study.

What is the purpose of the study?

The purpose of the study is to understand the lived experience of college students diagnosed with a chronic condition or illness at a public institution of higher education. A chronic condition is defined as a condition having a duration that has lasted, or is expected to last at least six months, have a pattern of recurrence or deterioration, have a poor prognosis, and produce consequences of sequalae that impact the individual's quality of life.

Where is the study going to take place and how long will it last?

The research procedures will be conducted at Eastern Kentucky University. You will need to come to Eastern Kentucky University's campus once during the study. This visit will take about 30-60 minutes.

What will I be asked to do?

Participants will be asked to schedule and participate in one interview that is audio-recorded that seeks to understand their personal experiences of being a college student who is diagnosed with chronic condition. Interviews may be conducted in-person or over the phone. This interview will be audio-recorded. Participants may choose a time and location that is convenient for them to participate in the research study. The primary researcher of this study will be conducting the interview and then transcribing the audio-recordings of the interview verbatim. Once the transcription process has begun each participant will be assigned a pseudonym in order to further protect each participant's identity. In order to ensure the security of the interview recordings, all audio files will be stored on the primary researcher's computer and password protected. interview transcription files will be password protected on the primary researcher's computer. All printed paper copies of interview transcriptions will be stored in a locked file box in the primary researcher's residence when not in use. Only members of the research team will have access to the audio recordings and transcription files. Once the primary researcher has completed the data analysis process, participants may be asked to review the findings of the study in person or by email in order to confirm or oppose the researcher's final conclusions. Informed consent letters, contact information, audio recordings, and transcribed data will be retained for three years along with all other documents from the study. After this retention period has passed, any paper records will be destroyed with a shredder. Any electronic data will be deleted after this period.

Are there reasons why I should not take part in this study?

Reasons a subject could be excluded from volunteering in this study includes: being under the age of 18, not currently enrolled as a college student, not medically diagnosed with a chronic medical condition, and inability to speak English.

What are the possible risks and discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm or discomfort than you would experience in everyday life.

Although we have made every effort to minimize this, you may find some questions we ask you (or some procedures we ask you to do) to be upsetting or stressful. If so, we can tell you about some people who may be able to help you with these feelings.

Additionally, you may seek help from the EKU Counseling Center for EKU students located at 521 Lancaster Avenue, CPO 52, Room #571 Richmond, KY, 40475-3152. You can also reach them by telephone at (859)622-1303. You may, however, experience a previously unknown risk or side effect.

What are the benefits of taking part in this study?

You are not likely to get any personal benefit from taking part in this study. Your participation is expected to provide benefits to others by providing insight to the personal experiences of college students with chronic conditions in order to identify possible support services that can be implemented to increase academic and personal success.

If I don't take part in this study, are there other choices?

If you do not want to be in the study, there are no other choices except to not take part in the study.

Now that you have some key information about the study, please continue reading if you are interested in participating. Other important details about the study are provided below.

Other Important Details

Who is doing the study?

The person in charge of this study is Kelley Harlan at Eastern Kentucky University. She is being guided in this research by Dr. Leslie Hardman OTR/L. There may be other people on the research team assisting at different times during the study.

What will it cost me to participate?

There are no costs associated with taking part in this study.

Will I receive any payment or rewards for taking part in the study?

You will not receive any payment or reward for taking part in this study.

Who will see the information I give?

Your information will be combined with information from other people taking part in the study. When we write up the study to share it with other researchers, we will write about this combined information. You will not be identified in these written materials.

This study is confidential. That means the information and data you provide to contribute to the study will only be viewed by members of the research team who have prior permission. When the interview audio recordings are not in use, they will be stored on the primary researchers computer under an encrypted file, meaning it is password protected. When the audio transcriptions are not in use, they will be stored in a locked file box in the residence of the primary researcher.

However, there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court (if applicable: or to tell authorities if we believe you have abused a child or are a danger to yourself or someone else). Also, we may be required to show information that identifies you for audit purposes.

Can my taking part in the study end early?

If you decide to take part in the study, you still have the right to decide at any time that you no longer want to participate. You will not be treated differently if you decide to stop taking part in the study.

The individuals conducting the study may need to end your participation in the study. They may do this if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if the University or agency funding the study decides to stop the study early for a variety of reasons.

What happens if I get hurt or sick during the study?

If you believe you are hurt or get sick because of something that is done during the study, you should call Kelley Harlan at (502)229-0393 immediately. It is important for you to understand that Eastern Kentucky University will not pay for the cost of any care or treatment that might be necessary because you get hurt or sick while taking part in this study. Also, Eastern Kentucky University will not pay for any wages you may lose if you are harmed by this study. These costs will be your responsibility.

Usually, medical costs that result from research-related harm cannot be included as regular medical costs. Therefore, the costs related to your care and treatment because of something that is done during the study will be your responsibility. You should ask your insurer if you have any questions about your insurer's willingness to pay under these circumstances.

What else do I need to know?

You will be told if any new information is learned which may affect your condition or influence your willingness to continue taking part in this study.

We will give you a copy of this consent form to take with you.

Consent

Before you decide whether to accept this invitation to take part in the study, please ask any questions that come to mind now. Later, if you have questions about the study, you can contact the investigator, Kelley Harlan at (502)229-0393. If you have any questions about your rights as a research volunteer, you can contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636.

If you would like to participate, please read the statement below, sign, and print your name.

I am at least 18 years of age, have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and voluntarily agree to participate in this research study.

____

Signature of person agreeing to take part in the study Date

____

Printed name of person taking part in the study

____

Name of person providing information to subject

Appendix B: Interview Guide

Name:
Age:
Major:
Expected Graduation Date:

1) Please describe your chronic condition.
    - When were you diagnosed? What medical care or attention is required? What symptoms do you often experience?
    - Do you consider yourself disabled?
    - Do you consider yourself to have a chronic condition?

2) Please describe what a typical day looks like to you.
    - Efforts taken to manage condition/healthcare routine?

3) What motivates you to pursue a college education?
    - What helps you have resilience to overcome the challenges you face such as those days when you're feeling worse than you know is your best?

4) Describe any challenges you may face at college related to your diagnosis.

5) Describe any positive aspects you feel you have experienced associated with being a college student who is diagnosed with a chronic condition
    - Do you feel like being at college with a chronic condition has made you develop your own sense of resiliency?

6) What makes you feel satisfied in your pursuit of your college experience?

7) How does your diagnosis impact your performance as a college student?

8) Describe any resources you may have utilized in order to help manage your diagnosis while at school.

9) What supports and resources would be more helpful in order to help you meet the responsibilities you hold both academically and personally?
    - Do you feel that being at college and having to be your own advocate adds to the stress or is that a role you are comfortable with?

10) Do you believe there are any common misunderstandings about college students who have chronic conditions?

11) How do you find balance between addressing your responsibilities of a college student and managing your chronic condition?

12) What have you learned about yourself as you have had to deal with your condition in the college setting?

13) Do you feel like your chronic condition is impacting the next steps that you take in your journey and as you plan for your future?

14) Is there anything I didn’t ask that you want to be sure to communicate to me about being a college student with a chronic condition?